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How Can We Better Meet The Information Needs Of Patients Newly Diagnosed With Brain Tumours?

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Purpose

In the Australian health care system, patients with brain tumours face a range of challenges in obtaining and understanding information, caused by complex medical care and often fragmented, multiple treatment sites and staff. Health professionals involved with these patients may be the most relevant source for understanding how information exchange can be improved. This study aims to explore information exchange as a component of care, and identify the most suitable interventions for improving information delivery.

Methods

Health care professionals involved with patients diagnosed with a brain tumour were interviewed using structured group concept mapping techniques. To identify elements of ideal brain tumour care and perceived relationships, data was analysed using qualitative and quantitative methods (thematic analysis, similarity matrices, multidimensional scaling, cluster analysis and pattern matching).

Results

Health care professionals proposed 647 existing or potential elements of care to assist patients newly diagnosed with a brain tumour. Thematic analysis enabled grouping of elements into 13 categories (eg access issues, finance, support groups) and selection of 42 elements for participant activities. Participants related these 42 elements to each other in a sorting activity, and rated each with regard to importance, feasibility and current provision. Similarity matrices, multidimensional scaling and cluster analysis of this data reduced these to eight clusters (tools for health professionals, psychological support, specialist services, multidisciplinary care, family support, information, communication, and practical services). Perceived relationships between clusters and average ratings were then displayed in two- and three-dimensional maps. Sixteen elements were identified with the most potential to improve care. For example, a care coordinator to follow patients and oversee their care was rated most highly for importance, and above average for feasibility.

Conclusion

This research has identified suitable intervention targets for improving information exchange between health professionals and patients with a brain tumour.

Research Implications

Interventions towards the targets identified could be more likely to be successfully implemented given their high importance and feasibility ratings by health professionals.

Clinical Implications

Provision of a care coordinator could have the greatest impact on information exchange between health professionals and patients with a brain tumour.

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